EDITORIAL 3

Decision analysis

# Whose lung is it anyway?

### T Treasure

Should the decision to operate be made by patients with NSCLC or their doctors?

he central point of the argument in the paper by Dowie and Wildman in this issue of Thorax1 is that it is the patient, not the doctors, who should decide whether to take the risk of an operation in the hope of curing lung cancer. I agree, and I know from working with a number of chest physicians on a regular basis that the patient's preference is genuinely central in decisions made about treatment. What is less certain is whether the choices being made are as explicit and as fully informed as would be necessary to implement decision analysis as espoused in this paper.2 My purpose is to ground the ideas in the context of current clinical practice and to see how near or far we are from patient determined decision mak-

### **MAKING THE DIAGNOSIS**

Firstly, the diagnosis must be known—including stage and cell type—and an estimate of prognosis made before the decision table can be entered. Dowie and Wildman's starting point is stage Ia nonsmall cell lung cancer. Clinicians will know that preoperative staging is never certain (if it were, we could claim a 100% surgical cure rate for N0M0 disease), but with increasing use of FDG-PET (fluorodeoxyglucose positron emission tomography) in addition to CT scanning and mediastinoscopy as appropriate, we get as near to a diagnosis of stage Ia disease as is currently possible.

### INFORMING THE PATIENT

We must also tell the patient. There are strategies for "breaking bad news" and it is never easy; it is we, the clinicians, who have to do it, but do it we must. In current practice not telling the patient can rarely be justified and we cannot have a decision analysis based on "gradual disclosure" and other forms of well intentioned evasion. Now the scene is set to enter the decision making process. We have a diagnosis and an informed patient. The next step is to populate the decision tree with data to inform the choice

## INSERTING DATA IN THE DECISION TREE

Dowie and Wildman refer to 4% and 8% as relatively fixed cut off rates for

surgical mortality for lobectomy and pneumonectomy, respectively. It is important to understood where these numbers come from.

Cardiothoracic surgeons have kept national registers of operations and survival figures dating back well over 30 years.5 These have been among the best in any specialty and any country. They have been collated annually and circulated to all members of the Society of Cardiothoracic Surgeons and used to reflect upon practice and an individual surgeon's performance. The data were provided voluntarily but have now been faulted for being made anonymous. When the Bristol balloon went up, the system was changed as a result of discussions between the GMC and the Society so that now all surgeons send in results for marker operations. All members doing thoracic surgery report 30 day mortality rates for lobectomy for lung cancer (without any adjustment for relative risk). Any surgeon whose results are above a threshold figure—and this is where the figures of 4% and 8% come from—can expect to be informed of the fact by the senior officers of the Society and for his or her health trust and medical director also to be informed. As I have pointed out elsewhere,6 this is an example of the way in which legislation intended to alter behaviour for the better may have another unintended consequence (the Rackman effect). In this instance it will make surgeons shy away from high risk cases to protect their annual summary statistic.

Surgeon specific data are available on 92 surgeons who performed a total of 1511 operations under the heading of lobectomy for cancer in 1999-2000. The median was 12 operations with an interquartile range of 5-27. Forty seven surgeons did 12 or fewer lobectomies a year (no more than a case a month). At this volume a single death (for whatever reason and no matter how high risk the patient) puts the surgeon above the arbitrary threshold (1/12 = 8.3%) but with hugely wide confidence intervals (95% CI 0.2 to 38.5). This is an inescapable problem if we subset data to ensure we are comparing like with like, the simplistic (and in my view worn out) "apples and oranges" approach to statistical analysis. The numbers we end up with are too small to achieve any stability in the event rate. I prefer the alternative approach of taking as large a proportion of the surgeon's practice as is feasible and intelligently applying a well informed and validated system of risk adjustment before making any comparisons or adjudication. However, it is an average risk over the surgeon's series of cases, not a level of acceptable risk for an individual patient, that was originally intended.

## PATIENT-DOCTOR COMMUNICATION

To return to our patient. She will know by now that she has cancer. She will perceive cancer, if untreated, as a death sentence (pace the slogan "cancer is a word not a sentence").4 She is likely to know that referral to a surgeon or the discussion of surgery with her physician means that she has been "lucky" enough to be one of the 10-20% where the cancer has not yet spread outside of the lung itself and surgical excision will (probably) cure it. What operative risk will she take? Dowie and Wildman are absolutely right. Faced with that situation a rational and well informed patient may willingly accept a risk of 10%, 20%, or even 40%.

I have had these discussions many times with patients and with colleagues. Surgery lends itself to this sort of debate more readily than many other treatments. Repeatedly in life and in the care of our patients we come to a point in the woods where the paths diverge and we must make a decision, but the surgical route is a one way street. Once the thoracotomy is performed, the risk is taken and any damage cannot be undone. Furthermore, it is not "the chance of dying on the table"1 (which is extraordinarily rare), but of dying slowly in the intensive care unit, of living on miserably short of breath, and/or eventually succumbing to cancer just the same. These are the downsides of the failure to deliver the hoped for uncomplicated cure and the difficulties that clinicians face in helping their patients towards the right choice for them. Even if the patient is prepared to take a 40% risk of perioperative death, can we possibly justify that as part of our clinical practice? There is an overall death rate which surgeons, anaesthetists, theatre staff, and ward nurses can cope with, but 40% would be carnage and expensive per life saved. I do not think that is what was envisaged.

Some clinicians will argue further that to hand over the decision to the patient is an abdication of our duty of care as doctors—it is a "cop out". For example, if I go to a professional for advice—a solicitor, an architect, a surveyor, a financial adviser, a plumber—I want their advice, not an overwhelming list of bewildering options. However, I think I

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am reasonably in agreement with Dowie and Wildman on this one. If my garage mechanic sells me a new gear box for my car with 110 000 miles on the clock, only for it to come to a halt a few weeks later with the next problem, I may wonder if I was given an even handed presentation of my options. I also know from years of experience in discussing prophylactic replacement of the aortic root in Marfan's syndrome<sup>10</sup> that, presented with the same set of probabilities, some opt to procrastinate (to come back for another echocardiogram next year) and others want to take the risk as soon as the surgical option is presented to them.10 11 Both are rational and I respect them equally. However, even in that relatively clear example of decision making we have puzzled over how to weigh the options. Should the operative risk be set against the probability of coming back alive for the next year's root measurement, or should it be a computation of life time risks for the two strategies?

#### **FUTURE CHALLENGES**

In welcoming this work I have two challenges for Dowie and Wildman. The first is a general one. Lung cancer, with 40 000 cases diagnosed each year, is common and rapidly fatal. Its care has fallen way behind that of the other common cancers.12 13 Five year survival rates for lung cancer in the UK are among the lowest in Europe<sup>14</sup> and resection rates that is, the proportion, expressed as a percentage of cases, where an operation is performed to eradicate the cancerare of the order of 10%, 15-18 half or less than in Holland<sup>19</sup> and the United States.<sup>20</sup> Elderly patients in the UK are even less likely to have surgery for lung cancer.15 18 Lung cancer care needs a rapid injection of resources. First in the queue for manpower expansion are oncologists and thoracic surgeons, but following on

will be the need for pathologists, anaesthetists, and other members of cancer teams. The London School of Hygiene and Tropical Medicine has established for itself a pivotal role in health policy, evaluation of health services and, in general, the numerate end of healthcare thinking. A drive for lung cancer from its Public Health and Policy Department would be a fillip to those working against enormous odds with this terrible disease.

The second is a more personal one. Dowie and Wildman's work seeks to inform decision making in lung cancer but one senses that thus far it is a theoretical exercise, untested in the actual process of doctor-patient interaction.21 I believe many of us have been using this approach for years, but we have relied on much less explicit rules and rather home spun approaches. Collaborative work with clinicians, combining theory with practice, is surely the way ahead. We have to make these decisions with patients all the time, albeit imperfectly. Let me publicly invite Professor Dowie and his colleagues to help us in exploring this approach in the care of our patients and to seek to validate and refine the process.

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